

A HOSPICE FOR THE PRE-BORN AND NEWBORN

A Kansas City Facility Provides Care for Babies with Severe Birth Defects and for Their Families, Too

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For most of the past decade, the co-authors of this article have been associated with Alexandra's House, a Catholic, charitable, perinatal hospice in Kansas City. A perinatal death is one that occurs to a baby during pregnancy, labor, or soon after birth. Alexandra's House provides care for babies who have only a short time to live, and for the families of those babies.

Because it is relatively new, the perinatal hospice concept is not well-known. Before we describe Alexandra's House, we should therefore say something about the idea behind it.

PRENATAL DIAGNOSES

The first prenatal diagnoses were made in the 1960s. Until then, caregivers often considered a perinatal death insignificant: a nonevent involving a nonperson. Today, however, prenatal diagnosis is an integral part of prenatal care. It involves:

- Targeted testing, dictated by known risk factors
- Testing of all pregnant women for certain conditions
- Routine ultrasound studies

Major birth defects, most of them discoverable prenatally, are today the most common causes of perinatal death. Statistics indicate that in 1996 approximately 6,400 U.S. infants died because of birth defects, a number constituting 22.5 percent of the total number of infant deaths (28,000). That year, birth defects were the leading cause of such deaths. They are the occasion for suffering and grief in a family.

PERINATAL DEATH AND GRIEF

In the early 1970s, when the neonatal intensive care unit (NICU) was a new phenomenon, most caregivers believed that close contact between a

mother and a very delicate newborn was not a good thing. If the baby were to die, these caregivers held, the death would cause an upsetting reaction in the mother.

However, a study conducted at that time showed that the conventional wisdom on the subject was entirely wrong.¹ The mothers in the study had no unduly upsetting reactions to physical contact with their babies, either at the time of death or later. There was no pathologic grieving. Indeed, later studies showed that contact with the baby and the development of a relationship was *beneficial* to the mother rather than harmful.²

But progress in this area was slow. In 1979, E. Lewis published an article intended to improve management of perinatal death by caregivers and to enhance effective mourning by the family.³ Lewis found that British hospitals still practiced what he called the "rugby pass management of stillbirths." He described it as "the catching of a stillbirth after delivery, the quick and accurate back-pass through the labor room door, to someone who catches the baby, rapidly covers it, and hides it from the parents and from everyone."⁴

In 1970 R. J. Knapp and L. G. Peppers published a study of parental reaction to perinatal death.⁵ Many of the parents involved in the study described feelings of isolation and abandonment, complaining that their physicians, who had been poorly prepared to deal with grief resulting from infant death, appeared aloof and unconcerned with the whole matter. Knapp and Peppers found that parents who underwent an abortion for birth defects in late pregnancy suffered the same grief as any other perinatal loss. (Many caregivers assume the opposite result: that abortion will resolve suffering.) In addition, these parents had other sources of distress, such as remorse over the

conscious decision to end the life of a baby and the possible disapproval of family and friends. And there were few people with whom they could discuss these feelings.

A generation ago, medical management of perinatal death included hiding the stillborn, especially one with birth defects, and preventing parents from having contact with a living baby with severe birth defects. But the reality is that *parents bond with the fetus in utero as a member of the family*. Perinatal loss causes family grief as does the loss of any other family member. The source of perinatal grief is “the loss of what might have been; the loss of experience of the future.”⁶ Proper mourning is needed in such deaths for the benefit of the parents, other family members, and—especially—the parents’ next baby.

BENEFITS OF PRENATAL DIAGNOSIS

By the early 1990s, somewhere between 73 percent and 83 percent of all birth defects were diagnosed by ultrasound studies. A common idea in the pro-life community is that the primary result of prenatal diagnosis of major birth defects is the promotion of abortions. This is not true; indeed, studies have shown just the opposite. If prenatal diagnostic studies are negative, this reassures the parents, who are relieved of concern that their child will have a serious defect. On the other hand, studies that *do* show the baby to have a severe birth defect allow the parents and physician to plan for that situation, including prenatal treatment (if indicated) and optimum management of labor and the birth of the infant. If the studies show significant or lethal birth defects, they will of course be the occasion for the onset of grieving by the parents. Forty years ago, parents learned that a baby had birth defects only after it was delivered, so they could only begin grieving after birth. Today, with prenatal diagnosis, they begin to grieve and suffer with the diagnosis, which frequently occurs approximately halfway through the pregnancy. This helps them deal emotionally with the reality of the child’s defect.

The authors of a study of this phenomenon have defined mourning as “the process by which an individual resolves a loss; that is, he or she accepts the reality of a change and reorients his or her internal representational world accordingly.”⁷ It turns out that memory is the engine that drives the successful mourning process. As one writer

has noted, “Memory facilitates the normal mourning processes essential for recovery.”⁸ Another has said that “memories propel the mourning process and after the death of a baby, there is little to remember.”⁹

STRATEGIES TO SUPPORT THE FAMILY

Caregivers can help people who, as the result of prenatal testing, have learned their baby has a severe birth defect. Some ways that caregivers can provide support is through:

- Conducting a private, compassionate discussion of the diagnosis. This discussion will take a lot of time and should perhaps involve, along with the mother and father, the extended family.

- Providing personalized prenatal care. For instance, some women pregnant with a baby with birth defects do not want to sit in a waiting room or birthing classes with mothers expecting healthy babies. Caregivers can make adjustments to help meet these types of needs.

- Gathering mementoes, especially the ultrasound photos. These are typically the first photos of any baby, and are especially important for those with fatal birth defects, especially in cases where the baby might die preterm. Some parents will ask for a 3-D ultrasound, even if they have to pay for it, just to have a more detailed look at their unborn baby.

- Appointing a consistent contact person for the parents. At Alexandra’s House, this is usually a nurse or social worker. The parents will have many fears, many concerns, and many questions. The contact person will be someone with whom family members feel a bond of trust, on one hand, and, on the other, someone equipped to help them sort through all the information they will be given. This person will be consistently available to the parents, providing them with support between doctor’s office visits. He or she will help the family prepare for the birth and death of the baby, and perhaps will help plan the memorial service, too.

- Referring the family to other caregivers, such as counselors, psychiatrists, chaplains, and other couples who have lost babies.

BIRTH PLANS

Parents of a baby with a severe birth defect should have both a plan for the labor and actual birth and a plan for the period after birth. For example, sometimes fetal monitoring is not only

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useless but also disturbing, because many babies with severe congenital anomalies have abnormal fetal heart rate patterns. (If, however, the parents want fetal monitoring, they should be allowed to have it.) Additionally, anesthesia and analgesia should be optimum for the mother.

The care plan should involve the participation of all those who are interested in the baby's life, the mother's labor, and the baby's delivery. The family should have an opportunity to see, dress, name, hold, and photograph the baby and to have it baptized. If the baby lives long enough to go to the nursery, caregivers should have in place a definite plan to reduce the suffering of both the baby and the family. The family should be involved at all levels of this planning.

As aids to memory creation, the family will want mementos of this event: footprints, a lock of hair, ID bracelet, blankets, and photographs—anything that helps propel the mourning. In some cases, the physician should consider aggressive care management, including cesarean section, so that the family can experience a baby with live birth. Because some of these delicate babies will not survive a normal delivery, it is on occasion ethical to do a cesarean section for this purpose alone.

After the baby is born, the caregivers should encourage rituals of remembrance.

Caregivers should maintain contact with the family for postbirth counseling, especially to give reports on postmortem and other studies.

THE IDEA OF THE PERINATAL HOSPICE

Cicely Saunders, an Englishwoman, began the modern hospice movement in 1948. The twin pillars of her work were relief of physical suffering and relief of existential suffering. Originally, pain was the major focus, and it was treated with opiates. The relief of existential suffering involved "giving some meaning to the situation, some deeper reality in which to trust," Saunders said.¹⁰ She made two other statements that are especially relevant to the perinatal hospice concept: "The family is the unit of care"; and "There is never a point where one should do nothing, nor a time when nothing can be done."

The first neonatal hospice in the United States was developed in Denver in the early 1980s. Many of the babies admitted to this unit weighed less than 1,500 grams; 21 percent had severe birth defects. Of the 759 infants admitted, 110

died. The founders soon realized that the unit's nursing staff needed some training in assisting families in the grieving, suffering, and mourning process. A family room was added to the unit, and the nursing staff became involved intimately in the process of counseling the parents of the dying infant.

Further development occurred through the work of Byron Calhoun, MD, a pioneer in the perinatal hospice movement in the United States.¹¹ He developed the concept in its mature form at Madigan Army Medical Center, Tacoma, WA, where he was chief of the perinatal service. Under Calhoun, the service's core care team consisted of the family itself, the relevant physicians, nurses, and a social worker. Psychiatrists, psychologists, anesthesiologists, chaplains, bereavement specialists, labor and delivery nurses, neonatologists, neonatal nurses, and ultrasound technicians were on call as needed.

Calhoun's ideas would have a significant influence on the founders of Alexandra's House.

ALEXANDRA'S HOUSE

Alexandra's House was begun by Patti Lewis, one of this article's authors, and named for her baby niece, Alexandra, who was born in December 1994 and died a little over a month later of Smith-Lemli-Opitz syndrome, a malformation disorder. Lewis, who had worked for almost 30 years as a cardiovascular nurse clinician, was so touched by the experience that she decided to offer care, free of charge, to families and babies suffering in similar situations.

Eugene W. J. Pearce, MD, this article's other author, met Lewis in the fall of 1998. Pearce was then course director of the continuing medical education program at Truman Medical Center, a teaching hospital for the University of Missouri-Kansas City. The year before, he had attended a Florida meeting at which Calhoun spoke. It was from him that Pearce first heard about the concept of perinatal hospice. Pearce immediately saw this as an advance in the health care of women.

He invited Calhoun to speak about the perinatal hospice concept to a meeting of Truman Medical Center physicians and nurses at an April 1999 meeting—and also to speak on the topic to a lay group later the same day.

Thus, on a Saturday evening, after Calhoun had met with the physicians and nurses at the medical center, he spoke to a crowd of nearly 200

laypeople gathered at a Kansas City hotel. This surprisingly large audience responded very favorably to both Calhoun and the perinatal hospice concept. The services that Alexandra's House would offer the community essentially began that night.

In October 1998, Pearce, Lewis, and Fr. Peter Jaramillo, the spiritual advisor for Alexandra's House, visited Madigan Army Medical Center to talk to Calhoun's staff. Later, they took a 12-week course in hospice care designed by Cliff Davis, MD, the former director of palliative care at Kansas City Hospice. They also received instruction in bereavement counseling. Lewis became a licensed foster parent, in order to receive abandoned, neglected, or terminally ill infants. Since the founding of Alexandra's House, the volunteers who work there have had instructions from various pediatric nurses on particular problems relating to the care of the delicate and ill newborn.

Alexandra's House received its first pregnant mother in 1999. The facility was then located not in an actual house but rather in Lewis's townhouse, one room of which she had converted into a mother-baby room. It was incorporated in 1997 as a Missouri not-for-profit organization and received 501(c)(3) (tax-exempt) status in 1999. Alexandra's House has both a board of directors and an advisory board. Lewis, who serves as the executive director and "house mother," is a full-time resident, available for any need, for which she receives a below-poverty-level stipend. This ensures that most contributions will go toward house maintenance and the needs of the ministry. Lewis is assisted by numerous dedicated volunteers, all unpaid.

The need for a hospice of this type is great. The Kansas City metropolitan area covers eight counties in Kansas and Missouri. In 1996, the area had an estimated 193 infant deaths, 61 of which were probably due to birth defects.

Alexandra's House differs from other hospice programs in that it is community-based, not hospital- or practice-based. The facility accepts referrals from any practice and attends births at any area hospital. A baby who survives birth can be brought to the house, where both the baby and the family will receive support. This support ensures that the family will not experience the feelings of isolation and abandonment. Alexandra's House's services are supportive, not

professional. The staff provides tube feedings or oxygen, when necessary. If a baby needs additional care, a local pediatric hospice organization is consulted. Alexandra's House does not charge for any of its services, although care can be time-intensive. Babies' stays at the facility have lasted as long as 12 weeks.

Referrals come from a variety of sources, primarily physicians and nurses who have heard about the facility's services. Other referrals have come from crisis pregnancy centers, churches, individuals, and from families who have received the facility's services. Pearce has developed a slide program on Alexandra's House and has presented it to a number of medical organizations in the area. In 2001 the *Kansas City Star* published an article about Lewis and the perinatal hospice, and this also served as a source of referrals.

The medical problems seen at Alexandra's House essentially cover the range of severe birth defects found in any relatively large population, including problems with open neural tubes; various trisomy disorders; problems of development of the anterior abdominal wall, the diaphragm, and kidneys; and undiagnosed anomalies that result in intrauterine fetal death. Not all of these babies suffer stillbirth or very early death, although approximately 90 percent do. Some babies survive for days or even weeks; and occasionally a baby will survive for six or eight months. One little girl, born with a posterior encephalocele—always considered fatal—turned three as this article was going to press. Four other children range in age from nine to 18 months. Alexandra's House has had several sets of twins; in one set, both babies died; in others, one baby died and the other survived. The facility has seen several families who have lost multiple children, which is very sad.

On the other hand, parents who have lost a baby sometimes invite Lewis to come to the hospital to witness the birth of a healthy brother or sister. (And women who are pregnant after having lost a baby, and naturally worried about losing another, sometimes ask her to accompany them on office visits to the obstetrician; they find her presence reassuring.) Lewis notes that, although loss of a child frequently leads to divorce, the marriages of all Alexandra's House parents have remained intact. So the facility sees great joy as well as sadness.

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ALEXANDRA'S HOUSE SERVICES

The basis of Alexandra's House is Christian love, mercy, and service. Its staff provides care to all who need it and accepts assistance from all those who share in its vision. The staff knows that the baby's parents and extended family grieve and suffer, and that they need support and service, both physical and spiritual. The staff's mission is to do what it can to give meaning to families' suffering and aid them in their healing.

After the parents have learned their baby's diagnosis, they come to the facility for an initial meeting and assessment of needs. When they are ready, the staff works with them to write a detailed birth plan. Staff members accompany the parents on visits to the physician's office and to the hospital for sonograms, serving the family as advocates, doing their best to provide a seamless stream of care.

Staff members attend labor and delivery, help coordinate baptisms or blessings, and help gather the needed mementos. They help preplan the memorial services and pay for the funeral if the family cannot afford it. They encourage siblings and extended family members to participate in all areas of the experience (if the baby's parents agree). Lewis has attended almost 160 labors and births over the years.

The period following the infant's death is a very important time for the family. Alexandra's House provides a minimum of three years of follow-up care. Staff members have provided grief support for most of the families (a few have chosen to receive such care from a pastor or private therapist). Some families, having bonded during the experience, have formed support groups. Over the years, Alexandra's House staffers have attended ice cream socials, barbeques, and picnics put on by families. Mothers of Alexandra's House babies sometimes come to the house for retreats—"slumber parties," they call them—during which they pray, share, make scrapbooks, "journal," and shed lots of tears—tears of healing.

Alexandra's House holds quarterly meetings (usually at the facility) and an annual retreat at a local center. Retreat sessions are informal and unstructured; family members commiserate with each other, talk to each other about their common experiences, and pass around their books of baby pictures. Everyone uses a lot of Kleenex, including the staff and volunteers. The facility recently began a separate session for fathers,

because they grieve so differently than mothers. Participants report feeling better after a retreat, having learned that they are not alone in their experience, that others share similar problems and stories.

THE MOST VULNERABLE AMONG US

In 2002, a donor provided a building for Alexandra's House. It is located in close proximity to Children's Mercy Hospital and to several others that provide high-risk maternal-fetal care. In addition to support services, the building provides guest rooms for parents who need respite after caring for a baby with special needs and for visitors from out of town.

Women pregnant with babies found to have critical birth defects live at Alexandra's House until birth, at which time the baby is usually taken to Children's Mercy Hospital, where the few that have serious but correctable problems receive high-tech care. Once discharged, the babies may return to Alexandra's House. To ensure that women carrying babies with defects won't have to travel significant distances during labor, local hospitals often ask Alexandra's House to provide housing for them. Once in a while, a baby is transferred to a NICU even though it has little chance of surviving, because the parents want heroic intervention. The facility provides care for those parents, too, when their babies are eventually taken off life support.

When Pearce talks to obstetricians about Alexandra's House, he reminds them why they went into obstetrics in the first place. They did so because they are interested in success and joy. They wanted to participate in that peak moment of the human experience—the birth of a newborn baby. They are willing to put up with loss of sleep, stress, and disruption of their lives in order to experience this joy.

Inevitably, however, every obstetrical physician diagnoses a baby as having a birth defect so severe that it probably will not survive. The obstetrician and his support staff then must shift from the cure system to the care system. Staff members at Alexandra's House experience this disruption of life (including sleep), too, as they travel this difficult journey beside families and physicians.

They have to be able to handle, with compassion and sensitivity, the bittersweet experience of an impending death of an unborn or a newborn baby. They cannot walk away after the birth, but,

rather, must accept the experience for what it is, seeing it as important to the family. They must acknowledge the child and its life, though brief, and not allow the family to feel ignored, isolated, and abandoned.

A program such as that at Alexandra's House reminds obstetricians and their colleagues to design services that meet the needs of such babies and their families. By sharing the experience of Alexandra's House, its staff hopes to encourage others to develop similar services in other communities. The mission of Catholic health care is to serve the needs of the poor and vulnerable. There is no greater vulnerability than that of a family experiencing the birth of an infant with lethal anomalies. ■

For more information, contact Alexandra's House at 816-931-2539 or www.alexandrashouse.com. Our e-mail address is alexandrashouse@kc.rr.com.

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